Adult Day Services in Iowa
Strengthening a Critical Home and Community-Based Service

Executive Summary

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August 3, 2007

Acknowledgements: We would like to thank the community professionals, adult day service providers, and caregivers who participated in this evaluation.

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The State of Iowa Code defines adult day services (ADS) as "organized programs providing a variety of health-related care, social services, and other related support services for 16 hours or less in a 24 hour period, to two or more persons with a functional impairment on a regularly scheduled contractual basis" (Iowa Code 231D and Iowa Administrative Code 321, Chapter 24). In 2001, Iowa had 83 facilities providing ADS, serving an estimated 1200 clients in 51 of the 99 counties. However, there was an absence of regulation and oversight of the ADS system, which had been already been implemented in most other states. With increasing pressure nationally and by state funding agencies for ADS to become regulated, the Iowa legislature adopted legislation that mandated all ADS providers to meet certain core standards and to be certified by the Iowa Department of Inspection and Appeals (DIA) in 2004. Subsequent to these changes, 45 of the existing ADS programs ceased providing ADS for various reasons, including closing the program and deciding only to provide respite services, leaving 38 certified and regulated ADS programs in 27 of the 99 counties to serve the state of Iowa as of 2007.

Even though ADS has been identified as a cost-effective service for older adults and people with disabilities, the expansion of ADS in Iowa has been slow to occur, evident by the significant decline of service providers since 2004. To identify the reasons for the lack of expansion of ADS in Iowa, the Department of Elder Affairs (DEA) contracted with the University of Iowa, School of Social Work to conduct an evaluation of the ADS system. This evaluation, conducted between January 1 and June 30, 2007, sought to assess the present needs and potential capacity of ADS in this primarily rural state subsequent to the policy and regulatory changes. To understand these needs across the state, the evaluation team collected information from caregivers and ADS consumers, ADS providers, executive directors of the Area Agencies on Aging (AAA), executive directors of professional trade associations, personnel from the Department of Elder Affairs, and other community-based professionals about 1) barriers to expansion of ADS in Iowa; 2) the effect of current laws and regulations on providing ADS; 3) the adequacy and availability of reimbursement for ADS; and 4) opportunities for growth of ADS in Iowa. This report summarizes the results of this inquiry.

Methods

Data were collected from the above identified sources using research methods designed to gather the most accurate information from each group of respondents, including *surveys*, *interviews*, and *focus groups*. Quantitative and qualitative data analysis techniques were employed. Information about ADS funding and reimbursement was reviewed. All research methods were approved by the University of Iowa Institutional Review Board (IRB) to ensure the protection of all participants.

Results

Program and Facility Description

This description of the existing ADS programs in Iowa was compiled from completed surveys (n=28) and administrator interviews (n=25). All but two of the DIA certified ADS programs identified themselves as non-profit organizations (92%, n=26); one was for-profit and another was government-based. Eighty-six percent of programs (n=24) were operating under the auspices of a parent organization, such as a long-term care facility, retirement community, or county-wide aging services provider. Whether or not a program belonged to a parent organization often determined the amount of control, decision making

responsibilities, and the amount of knowledge that program administrators had about the budgets, reimbursement, and funding for their service. Eight (29%) of the programs were also accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF), a national accreditation program. The majority of the programs (n=18, 64%) reported that they provided a combination of social and medical services. The remaining ten providers (36%) identified their program as "social" only.

The majority of ADS programs were concentrated in the central and eastern portions of the state. The remaining programs were more widely distributed in other areas; however, the most distant counties in each quadrant of the state, also the most rural, are not served by ADS programs. While some of the ADS programs were small, with the ability to serve between 6 and 20 clients (n = 9, 32%), most (n = 14, 50%) were mid-size with the ability to serve between 21 and 40 clients. Three programs (11%) were able to serve up to 65 clients. In 2006, the programs were operating at 70% of their total capacity, which was improved from 2004 and 2005. The majority of the programs (89%, n=25) were open 5 days per week and most programs (71%, n=20) were open for at least 8 hours per day. To meet the needs of their clients, programs employed between 2 and 12 staff, both part and full-time, who possessed certified nursing, activities, or registered nursing degrees. Few facilities employed a full-time social worker or someone to work with families. The ADS providers on average maintained a 2:6 staff to client ratio.

Fifty-four percent (n=15) of the ADS programs served only individuals over age 60 or those with some form of dementia; 11% (n=3) served only individuals with mental retardation or other developmental disability. Twenty-five percent of ADS programs (n=7) provided services to both groups. Clients ranged in age from 16 to over 100 across the programs, with younger clients averaging 37 years old and older clients averaging 89 years of age.

Barriers Related to the Expansion of Adult Day Services

Data from the Department of Elder Affairs, professional trade associations, AAA, community focus groups consisting of professionals and caregivers, and ADS providers identified multiple barriers to the current ADS system and for the future expansion of the service in Iowa.

Systemic Barriers Systemic barriers pertain to having a sufficient infrastructure to support the growth of ADS. Some of the systemic barriers were endemic across the state, while others were present within the ADS network. These barriers included:

- Lack of accessible, affordable, and available transportation
- Lack of adequate funding and reimbursement
- Lack of legislative support for adult day services
- Strength of the nursing home and assisted living lobby
- Lack of political clout of Iowa Adult Day Services Association (IADSA)
- Lack of recognition of the cost-effectiveness of adult day services compared to long-term care facilities
- Adult day service regulations too closely mirroring assisted living regulations
- Stigma felt by older adults who may benefit from adult day services
- Values of elders in rural areas of wanting to care for one's family member
- Lack of organizational infrastructure within IADSA, including website, paid staff, and communication systems

Community Barriers There were many community-level barriers that were identified by participants as prohibiting the growth of ADS in Iowa. These barriers pertained to factors that existed in both urban and rural communities that either inhibited people from using ADS or developing the program. These included:

- Limited support and interest in adult day services in many communities by professionals, as well as potential caregivers and consumers
- Lack of financial resources in the community to support adult day services (mostly seen in rural areas)
- Limited knowledge about adult day services among health and social service professionals, including the difference between "respite" and "adult day services"
- Clients referred to adult day services too late (needing 24 hour long-term care)
- Lack of accessible, affordable, and available transportation to transport individuals to adult day services
- Geographic distance people have to travel to adult day services
- Rural communities viewing current adult day services regulations as promoting an "urban model" of care
- Lack of enough participants in a given rural community to sustain a free-standing facility
- Rural communities viewing adult day services as a "community service" not a "business"
- Growth of assisted living facilities throughout the state
- Competition between providers, specifically home health care, assisted living, adult day services, and nursing homes, for clients
- Lack of qualified staff who are interested in working in adult day services
- Different populations of clients (older adults and those with disabilities) not wanting to attend the same adult day service program

Underlying both the systemic and the community-level barriers was *the lack of time* that the ADS administrators had to work proactively to address the aforementioned barriers to their program. It was not unusual for the administrator to be performing a variety of duties at the ADS, including cooking, programming, nursing, family support/social services, personal cares, particularly bathing, and providing transportation. These additional duties, which *could* be performed by other staff, removed the administrators from the roles that would assist in growing their businesses, such as marketing, public relations, continuing education and training, lobbying, and building community and statewide networks within the larger continuum of care for older adults and those with disabilities. Due to poor funding, which will be discussed below, ADS providers had few dollars available to hire additional staff to perform these other duties; thus, the burden falls on the administrators' shoulders.

Program Costs and Funding Sources and Barriers

The costs for clients to attend ADS for a fully day ranged from $36-$64 dollars per day, averaging $49.56. Other services, such as transportation and assistance with activities of daily living, specifically bathing, were additional costs for most of the programs. Programs reported that they received third party reimbursements for 75% of their participants, while 25% were private pay in 2006. Ninety-three percent (n = 26) of the ADS programs indicated that they received Title XIX Home and Community-Based Waivers in 2006. Based on the average daily cost of ADS ($49.56), if the facility was reimbursed at the $43.59 rate, they would lose approximately $6 per day for each person receiving the Waiver. However, based on the unit cost analysis ($55.00/day), the facility would lose close to $12 per day on each participant receiving the Waiver.

Other sources of funding accessed by ADS programs to support their clients included:

- AAA contracts – 70% of ADS providers
- Veteran Affairs benefits, ranging from $47/day to $64/day - 61%
- Senior Living Trust Program - 43%
- Older American's Act, specifically the National Family Caregiver Support Program – 36%

- Child and Adult Care Food program - 43%
- Long-term care insurance policies - 46%
- Other sources (grants from United Way, donations, proceeds from fundraisers, and/or the parent organization off-setting some program costs) - 32%

Funding Barriers A number of funding barriers were identified by the respondents, which impacted their ability to grow the ADS program. These included:

- Reimbursements rates too low
- Adult day service providers experiencing difficulty "breaking even"
- Lack of knowledge among adult day service administrators about funding and reimbursement sources
- Inconsistent or unavailable information about funding and reimbursement from official sources
- Difficulty attracting private pay clients
- High cost for certification
- Lack of adequate adult day services "start up funds"

Adequacy of Third Party Reimbursements

Based on the analysis of the third party reimbursement system, the ability for the ADS industry to be financially viable without additional or stronger funding and reimbursement streams is questionable. Additional fundraising, grant writing, and accessing dollars from other community entities, such as the United Way or receiving assistance from a parent organization was the only way for ADS to offset costs. To secure additional revenue required a considerable amount of time on the part of the administrator, which most did not routinely have due to staffing shortages. For smaller, less established ADS, parent organizations offset costs through funding from other programs or funding sources. Free standing, less established ADS providers were at greatest jeopardy for being closed due to funding. It is also these programs that have fewer staff and require the administrator to provide more direct care, decreasing time available for fundraising and grant writing.

Review of Iowa Code 231D and Iowa Administrative Code 321, Chapter 24

Respondents were not always familiar with the details of the Iowa Code and Administrative Rules related to ADS, although all participants knew that certification requirements had been created. It was agreed by all participants that the Code and Rules provided for the quality of service that ensured the safety of participants and a framework for ADS that would be similar across the state. The primary concerns expressed by respondents included:

- Adult day services regulations limited the ability of ADS to be successful in rural areas
- Administrator training and education was not required in the ADS Legislative Code
- Fee for certification was excessive
- ADS Code and Regulations does not reflect the differences between Assisted Living and ADS programs

Technical Assistance Needs and the Provision of Technical Support

The ADS providers and other respondents identified many areas where technical assistance was needed to strengthen the ADS system. These areas included:

- Marketing and public outreach
- Identifying future clients
- Building community relationships
- Measuring staff competencies

- Staff training
- Obtaining best practices for adult day services
- Administrator training and development
- Understanding reimbursements, funding and budgets
- Understanding adult day service regulations
- Business model development
- Mentoring for adult day service providers

In addition to the individual ADS programs, the Iowa Adult Day Service Association (IADSA) might also benefit from technical assistance. Not all ADS providers in the state were members of the association and several did not realize that there was a state ADS association. Areas of needed technical assistance include:

- Development of an infrastructure and leadership roles
- Development and maintenance of a website to facilitate communication
- Development of a communication network to distribute information in a timely manner among programs and between state regulating bodies and programs

One of the most significant questions that ADS providers and executive directors from the AAA asked was related to who would provide technical assistance to the ADS. It was the consensus of participants that the current entities in the State were not viable choices. One possible resource would be the American Association of Homes and Services for the Aging (AASHA) which has initiated a plan for pilot partnerships to be formed between state adult day associations and state associations of Homes and Services for the Aging. IADSA is participating in this partnership. This may be a first critical step in strengthening the IADSA.

Summary and Recommendations

This evaluation produced findings that have been found in other research and evaluations of ADS in the United States. In 2002, the Partners in Caregiving[1] initiative determined that ADS in Iowa was operating at a utilization rate of 58%. The current evaluation found that ADS had a current utilization rate of 70% in 2006, which demonstrates growth in the program over the last five years. The unit cost daily fee of ADS in Iowa has increased since the 2002 evaluation from $45 to $55. The average daily rate has also increased from $42 to $49.56. Thus, while the unit cost has increased approximately $10 in the last five years, the private pay fee has only increased approximately $7. The percentage of Medicaid eligible ADS participants has greatly increased over the last five years. The Partners in Caregiving evaluation reporting that 46% of participants were Medicaid eligible, while current evaluation determined that 75% of current ADS participants are being funded through third party reimbursement, most commonly the Medicaid Waiver program. This, combined with low reimbursement rates, has resulted in programs operating in deficit situations.

Other evaluations of ADS support the findings from this evaluation of the Iowa ADS system. O'Keeffe and Siebenaler[2], in an evaluation of the ADS program in five states that was funded through the U.S. Department of Health and Human Services, determined that none of the ADS programs that were evaluated could meet their costs through only private pay and third party reimbursements; all of the programs relied on other sources of funding, such as donations, fundraising, or subsidies from parent

[1] Partners in Caregiving (2002). National study of adult day Services. Wake Forest University, School of Medicine.
[2] O'Keeffe, J. & Siebenaler, K. (2006). Adult day services: A key community service for older adults. Office of Disability, Aging, and Long-term Care Policy, U.S. Department of Health and Human Services.

organizations. Like the present evaluation, O'Keefee and Siebenaler concluded that "reimbursement rates were not sufficient to meet costs" of ADS programs (p. ix). O'Keefee and Siebenaler also found that structural barriers prevented the growth and expansion of ADS. Issues such as transportation, lack of professional and caregiver awareness of ADS, and the need for public education on the benefits of ADS were needed to be strengthened before programs could grow.

At the current time, ADS programs in Iowa are surviving because of highly dedicated administrators and staff who are willing to spend long hours and their personal time trying to grow their business and serve their communities. Programs are also surviving because some parent organizations are willing to provide financial resources to keep the doors of this service open despite financial performance. However, should either of these factors change, it is unclear how viable this home and community-based service will be without outside intervention. From the data that were collected, recommendations emerged that will help create a stronger ADS infrastructure and potentially ensure the longevity of this program in Iowa. Some of the recommendations require policy changes, while others require the development and support of the ADS industry itself. All of the recommendations are related to each other, but identify pertinent aspects of the identified issue.

1. **Development of state-wide task force:** Given the number and variety of problems and issues identified by the participants in this statewide evaluation, and the very limited time that the present program administrators had to address these issues, the establishment of a statewide task force to systematically address the issues identified in this report would ensure that ADS would become a more stronger and more viable service for older adults in Iowa. The task force could be comprised of experts from Iowa and outside the state on ADS, business developers, leadership trainers, legislators and program evaluators, advocates for ADS, as well as program administrators, consumers and their caregivers.

2. **Mandatory training for ADS administrators**: Many ADS administrators lack specific administrative training, which is essential to building a successful program. Additionally, many had limited knowledge about the intricacies of reimbursement systems and regulations that are needed to run an ADS. Administrative training, which should include accounting/budgeting, funding, regulations, supervision, and marketing/public education information, would provide them with the necessary knowledge to develop a business model and successfully navigate the certification process. Establishing a mandatory training program for ADS administrators would also assist in the distribution of accurate information on funding, reimbursement, and regulations that is currently lacking with in the ADS system.

3. **Evaluate the affordability and accessibility of transportation in Iowa:** Overwhelmingly, transportation was identified as the most significant barrier to the growth of ADS. ADS requires individuals to leave their homes to access the service. For many caregivers, it is unrealistic for them to serve as the primary source of transit for the care recipient to and from ADS due their impaired health status, inability to drive, employment status, or overall feelings of stress and burden. The ADS programs that did not provide transportation services consistently identified this as one of the factors that was limiting their growth and expansion. However, due to funding, they were unable to afford to offer this service. Determining a way for transportation to be built into the ADS system is one clear way to strengthening this service. The lack of transportation is currently a regional, county, and city issue. For those people in the most rural areas of Iowa, the lack of transportation to and from services excludes them from participating in many of the health related services that could improve their quality of life as they age.

4. **Increase funding through the Title XIX Home and Community-Based Waivers and other sources**: Daily reimbursement for ADS is too low and is one of the contributors for providers

losing money. On average, providers receive $12.00 less than their unit cost for ADS. Raising the daily reimbursement rate for ADS may also trigger need to raise total cap from $1084 per month. While it is recognized that Medicaid dollars are limited and priorities must be chosen, approximately three out of four ADS consumers rely on third party reimbursement to pay for their service. Thus, sufficient funding from the Medicaid Waiver program to support ADS programs is essential.

Additionally, other sources of funding from the state must be explored to support ADS. With it taking ADS providers up to five years to reach a break even point, start-up funds for ADS programs and reconsidering the certification fee are needed. ADS programs have the potential to save the state million of Medicaid dollars that would be directed to long-term care services for dependent individuals. Unless ADS programs have sufficient reimbursement and funding, they will continue to financially struggle.

5. **Develop an infrastructure to support the network of ADS programs**. At the current time, the ADS service network lacks the necessary infrastructure to be successful. The exchange of information between ADS providers, as well as between state agencies and ADS providers is not effective with some providers having certain pieces of information and others having minimal information. The needed infrastructure would include:
    a. Establishing and supporting a system of communication *between* individual ADS providers and *between* ADS providers and state entities (DIA, DEA, IADSA), which would include regular mailings and websites detailing changes in reimbursement and funding, regulations, and providing a forum for people to receive answers to their questions about running an ADS.
    b. Mandatory training for ADS administrators as described in recommendation #1.
    c. Strengthen IADSA to facilitate communication and efficiency in providing critical information to program administrators and to offer support to administrators. At least initially, this may require providing technical assistance to and funding for a staff person to develop an association website and list serve between IADSA members.
    d. Mentoring system for either new ADS programs or programs that are looking to grow or expand their business.

6. **Consider the differences between rural and urban ADS programs**. There is a need for ADS programs in rural areas. However, the sentiment of the current providers is that ADS in rural areas will never be like the programs that are found in areas with populations over 100, 000. Additionally, it is questionable if the most rural areas of the state could support an ADS. The Partners in Caregiving report indicates that the populations of communities must be at least 20,000 to support an ADS, with at least 1% of the population (200 people) who could be potential consumers of the ADS service. With over 50% of the counties in Iowa having a *county population* of less than 25,000, an ADS program such as one that is found in a more urban area of the state is not feasible. The geographic distribution of ADS programs demonstrates that the most rural areas of Iowa are underserved and from the data that were collected caregivers are struggling with how to obtained respite and therapeutic home and community-based services for their care recipients.

    ADS programs are needed in rural communities, but considerations need to be made about how ADS programs in these areas of the state can be successful. Options, such as a tiered system of certification for different geographic areas, devoting greater technical support and mentoring to rural communities during the implementation of and the first years of the ADS, and creating greater flexibility for the use of existing services, such as nursing homes, for ADS programs, should be examined to determine feasibility. Additionally, support for transportation services to

assist clients in accessing ADS services should be considered. Health and social service professionals in rural areas want to provide an ADS and feel that it would greatly benefit their community. But, until ADS is structured in a way that is conducive to the constraints of many rural areas, ADS will most likely not be able to be provided. Examining how other rural states provide ADS services many be an initial step in this process.

7. **Implement a statewide public education campaign about ADS**. The focus groups revealed a lack of knowledge that health and social service providers had about ADS. This was particularly concerning because the professionals who attended the focus groups interfaced with clients on a daily basis who could be referred to ADS programs. This education would not only assist in educating people about ADS, but also laying the foundation for professionals to consider implementing an ADS in the underserved areas of the state.

8. **Education for providers about the difference between in-facility respite care and ADS**. As indicated previously, confusion still exists over the terms "respite" and "adult day services". Community and long-term care professionals used the words interchangeably. ADS providers also were unclear about what constituted a respite service versus what they provided through their program. It was found that long-term care facilities continued to refer to their respite service as ADS even though they were not certified through the DIA. This issue was particularly confusing for caregivers who thought they were sending the care recipient to one service only to learn that it could not be reimbursed through the waiver due to regulatory issues.

9. **Identify an entity that will help strengthen ADS in Iowa**. ADS is needed in Iowa; however, the service must be strengthened. Iowa has several strong ADS programs; however their administrators do not have the time to mentor smaller ADS programs. For the ADS system as a whole to be strengthened, some entity needs to step forward to provide the leadership and mentoring that is needed and desired by the current ADS programs. Unless a key person or entity is identified, such as the Iowa Association of Homes and Services for the Aging, it is questionable if many of the current programs in the state will exist in the next 5 years. The pilot program that is being developed between IADSA and the Iowa Association of Homes and Services for the Aging is only one step in this process and cannot be viewed as the only solution to this issue. The establishment of other initiatives, including an ADS mentoring system, hotline for answering regulatory and reimbursement issues, and an on-going training program, must also occur.

10. **Conduct a needs assessment of Home and Community-Based Services in rural areas**. While the focus groups were specific to ADS, professionals discussed other service needs that individuals faced in their communities. A common theme that developed in these discussions was that older adult and MR/DD populations do not want to mix and participate in services together. A needs assessment should look not only at needed services, but also an analysis of funding streams to support future programs. Additionally, a needs assessment should examine locations throughout the state that would be strategic locations for services so that individuals from a greater geographic area could access support. While this type of needs assessment would be time intensive, it would be extremely valuable as the state looks at the provision of services for older adults over the next 10 to 15 years.